

## **PSYCHOSOCIAL IMPACT OF SICKLE CELL DISEASE ON FAMILIES IN BASRA, SOUTHERN IRAQ; AN EXPERIENCE OF CAREGIVERS**

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### **ABSTRACT**

Although there are many studies concerning the clinical impact of Sickle Cell disease, however, studies about the psychosocial impact of the disease on the family are lacking. This study was carried out to assess certain psychosocial aspects of the illness on families of patients with sickle cell disease and the impact of disease severity on these psychosocial variables. The psychosocial impact of sickle cell disease on families was assessed using Sickle Cell Disease Burden Interview which includes; financial burden of the disease, the disruption of family interactions, the disruption of routine family activities, and caregivers coping ability and feelings towards the affected child. A total of 130 caregivers of patients with sickle cell disease registered at Basra Center for Hereditary Blood Diseases were recruited over the period from the first of April till the end of December 2013, the patient's age ranged from 6-18 years. The study revealed that sickle cell disease has moderate and severe impact on financial status of the family (54.6% and 40.8% respectively), with a mean of  $6.11 \pm 1.57$ , and routine family activities (41.5% and 34.7% respectively) with a mean of  $10.03 \pm 2.17$ . Concerning family interaction and coping abilities, the caregivers didn't report any problem in 70.7% and 73.8% respectively. The financial status of the family was significantly adversely affected by educational level of caregiver and his/her employment, number of affected siblings and frequency of blood transfusions,  $P < 0.05$ . In addition, routine family activities were significantly affected by care givers employment, number of affected siblings and frequencies of hospitalizations and vaso-occlusive crises,  $P < 0.05$ . The present study concludes that families of patients with sickle cell disease experience significant financial difficulties, and disruption in routine family activities. However, most of these families didn't experience significant family interaction and coping problems.

**KEYWORDS:** Sickle Cell Disease, Psychosocial Burden, Family

### **INTRODUCTION**

Comprehensive medical care, with evidence-based strategies provided by experts in sickle cell disease (SCD) and education of the parents about the early detection of the most common complications, have dramatically decreased SCD-related mortality and morbidity over the last 20 years. <sup>(1)</sup>

Hemoglobinopathies including the thalassemias and sickle cell disease are prevalent inherited disorders in most Arab countries mainly due to high level of inbreeding with consanguinity rate in the range 25-50%. <sup>(2)</sup> In Basra, sickle cell gene is reported in all areas with an overall frequency of sickle cell trait of 6.48%. <sup>(3)</sup>

The assessment of the clinical and laboratory indicators of an individual's illness may not be adequate to define the extent of the effects of the illness on individuals with SCD. <sup>(4)</sup>

Chronic illnesses including SCD adversely affect the patient's self-image and self-esteem and inducedistressful emotions, anxiety, depression, feelings of helplessness, as well as illness-related factors like changes in physical appearance or bodily functioning. <sup>(5)</sup>

In addition to the physical and psychosocial effects of SCD on patients, having a child with SCD may affect parental relationship, including lack of time with the siblings, communication problems, higher divorce rates and increased relationship conflict. <sup>(6)</sup>Families of children with SCD may miss work, experience increased family stress, and increased disease care demands, which is due in part to the unpredictability of pain crises care in SCD. The primary caregivers often feel frustrated and hopeless because of lack of support by family and friends during child's pain crises. <sup>(7)</sup>

Illnesses associated with SCD exerts significant burden to patients and their families and contribute to poverty by leading to loss in productive time and money on the side of the affected persons/families, retardation of their economic development and losing job sometimes, and difficulty in dealing with daily requirements of other family members, causing a further impact on the family. <sup>(8)</sup>

Since the patient with SCD live with the disease throughout the life-span of patients, the medical and psychological costs of managing the disease are high <sup>(9)</sup>Economic status of family in turn influences the care and management of these patients and thus influences the psychological, social and economic problems encountered by families of children with SCD. <sup>(10)</sup>

Family coping is an important factor to improve the quality of life of children with SCD. Families need different types of support by sharing of roles and responsibilities between parents, with grandparents, and other adult relatives and also by education of other members mainly siblings and education of extended family members by health professionals working with children with SCD. <sup>(11)</sup>

Social support outside of the family like from relatives and friends is also beneficial to all members of the family, both physically and psychologically. <sup>(12)</sup>

This study was carried out to assess the psychosocial burden of the illness on families of children and adolescents with SCD in Basraand to look for the impact of disease severity on psychosocial variables among families of these patients.

## PATIENTS AND METHODS

A descriptive study has been carried out on caregivers of patients with SCD who have been registered at the Center for Hereditary Blood Diseases (CHBD) at Basra Maternity and Children Hospital from the first of April till the end of December 2013. The caregivers of 130 patients were recruited, the age of patients ranged from 6-18 years.

For recruitment in the study, the caregiver need to satisfy the following criteria; caregivers must have attended the CHBD at least 3 times before the interview to allow an adequate period of interaction and the child must have been living with the caregiver for a minimum of 1 year before the interview. <sup>(13)</sup>

Data included educational level of the caregiver and his/her employment, numberof siblings,and how many siblings are affected with SCD.

Clinical data obtained were age at presentation, number of hospitalizations in the previous year, and number of blood transfusions (BT) in previous year.

The patient is classified to have severe disease when the frequency of vaso-occlusive crises (VOC) requiring hospitalization is  $\geq 3$  times/year, frequency of blood transfusion (BT) is  $\geq 3$  times/year, at least one cerebrovascular event (CVA), acute chest syndrome (ACS) and /or avascular necrosis of bone.<sup>(14, 15)</sup>

The state of the child during the interview of the caregiver was recorded; whether in steady state or not. Baseline steady state is defined as a steady hematocrit and hemoglobin values over a given period of 2-3 clinical visits at 4-6 weeks interval and a state of wellbeing without any symptom or sign suggestive of crisis, infection, and other diseases established by a careful history and complete physical examination.<sup>(16, 17)</sup>

An informed consent was obtained from the caregiver of the patient for recruitment in the study. This work was approved by the Ethical Committee of Basra Medical College.

Sickle Cell Disease Burden Interview (SCDBI) questionnaire was used to investigate the impact of SCD on the family. It included four domains; financial burden of the disease, the disruption of family interactions, the disruption of routine family activities and caregivers, coping ability and feelings towards the affected child.<sup>(13, 18)</sup>

The questionnaire contains a total of 16 questions: three questions for each of the family finances and interactions, and five questions for each of the routine family activity and parental coping ability.

The questionnaire was translated to Arabic language with regard to Iraqi dialect and cultural context, the translation procedure was helped by two professional translators, and then submitted to 10 caregivers to determine whether the questions were clear, understandable, and in a logical order. Moreover, three pediatricians and one clinical psychologist who had experience in working with SCD patients and their families were asked to express their views on whether they consider the questions of questionnaire to be representative of the psychosocial burden of SCD on caregivers or if additional statements need to be added.

The internal consistency of the questionnaire was carried out by calculating the Cronbach Alpha coefficient. The internal consistency of the questionnaire questions making up each sub-scale was 0.78.

For impact on family finances and family interactions, total score of 0 indicates no impact; 1–3 as insignificant impact; 4–6 as moderate impact; and scores between 7 and 9 as severe impact.

For impact on routine family activity and parental coping ability, total score of 0 implies no impact; 1–5 as insignificant impact; 6–10 as moderate impact; and scores between 11 and 15 as severe impacts.<sup>(18)</sup>

Statistical analysis was done using the Statistical Packages for Social Sciences (SPSS) software version 17.0. Comparisons of proportions were performed by crosstab using Chi-Square test. Analysis was also done among multiple groups by using One Way Analysis of Variance (ANOVA) test. For all tests P value of  $<0.05$  was considered as statistically significant.

## RESULTS

A total of 130 patients with SCD and their caregivers were included in the study; 81 (62.3%) males and 49 (37.7%) females. The age of patients ranged from 6-18 years with a mean age of  $10.79 \pm 3.32$  years. Mean age for male

patients' was  $10.42 \pm 3.16$  years and for females  $11.34 \pm 3.50$  years, (Table 1).

Concerning caregivers working (33.8%) and in an 18.5% of patients with SCD, the caregivers are not the parents. Apart from parents, all other caregivers were the grandmother, mostly because of parental divorce except in 3 cases because of death of one of the parents. Most of the patients with SCD have other affected sibling (s) (90.1%), and among these families (32.4%) have  $\geq 2$  affected siblings, only (3.1%) have higher education. In addition, a high percent of caregivers are not.

The influence of SCD on different psychosocial components on families was assessed for each domain, (Table 2). More than two-thirds of caregivers stated that time spent caring for the child made them lose income or financial benefits, and that the expenses of the child's illness adversely affected the provision of their family's basic needs such as food and clothing, while (62.4%) have taken a loan to meet the extra financial expenses of the patient's illness mainly from relatives and friends.

In addition, most of caregivers (66.9%) mentioned that caring their children with SCD made them neglecting other family members, and it was difficult for their affected children to attend school (83.8%) and assist in household activities (63.1%). Difficulties in engaging in other necessary activities and disturbed recreational activity were reported in only (12.3%) and (20%) of families respectively.

Half of the families reported that their child's illness didn't cause tension at home, while in (43.8%) there was occasional disagreement among family members because of the child's illness and more than half of families have experienced occasional marital disharmony.

Only (26.2%) of families have frequent difficulties in coping with their child's illness. While more than (50%) of families didn't report difficulties in accepting responsibility of child illness, feeling depressed, angry and stigmatized because of the child illness.

Concerning the total and mean scores of the 4 main domains; it was found that SCD has moderate and severe impact on financial status of the family (54.6% and 40.8%) respectively. In contrast, the disease has moderate and severe impact on family interaction only in (19.3% and 10%) respectively. In addition, 34.7% of families have severe disruption in routine family activities and 41.5% have moderate disruption, while most of them (73.8%) didn't experience significant coping problems, (Table 3).

The impact of the condition of the child with SCD during interview has revealed that the condition of the child with SCD during crises significantly affects the financial and family routine activities compared to those in steady state,  $P < 0.05$ , (Table 4).

The effects of different socio-demographic and clinical variables on psychosocial burden scores were also assessed; it was found that illiterate and not working caregivers experience a significant financial burden and family interaction. In addition, caregivers other than parents suffer a significant impact on financial status, while the presence of  $\geq 2$  affected siblings adversely affect the financial status and routine family activities, (Table 5). Concerning clinical burden variables; those with frequent hospitalizations  $\geq 3$  times/year and  $VOC \geq 3$  times/year have a significant burden on routine family activities, while frequent  $BT \geq 3$  times/year adversely affect financial status. None of the socio-demographic and clinical variables has a significant impact on coping of families with their child's illness, (Table 5).

## DISCUSSIONS

This study assessed the psychosocial impact of SCD on the families in Basra, where the frequency of the disease is high in different areas of Basra.

The current study revealed that (54.6%) of caregivers have completed their primary education, this is lower to what was reported by Wasomwe et al (70%) in Zambia,<sup>(19)</sup> while Ohaeri et al in Nigeria reported that the majority of caregivers (68.1%) had at least secondary school education.<sup>(18)</sup> Low educational level of the caregiver can affect their understanding of SCD and adversely influences the way they care for the child and this increases the impact of illness on the family.<sup>(19)</sup> In addition, around one third of caregivers were not working, a similar result (38.3%) was reported by Wonkam et al,<sup>(20)</sup> another factor that poses an additional burden on these families.

Vaso-occlusive crises (also known as acute painful episodes) are the core feature of SCD and the most common cause for emergency hospital admissions and also for frequent hospitalizations of these patients.<sup>(21, 22)</sup>

Most patients in this study have been hospitalized during the year prior to the study mainly due to VOC (87.7%). Akar et al in Kuwait and Brown et al in Nigeria reported VOC in 63.2% and 61.5% respectively of admitted children with SCD.<sup>(23, 24)</sup>

Despite the nature of healthcare in Basra is free-for-service basis, the financial burden of SCD on the caregivers and their families is considerable. This can be attributed to the low socioeconomic status of the studied families; as around one third of caregivers were not working, and more than two thirds of them are with no or low education.

In addition, most of the caregivers (67.7%) in this study lost income due to time consuming caring for their children with SCD which significantly contributes to the financial impact practiced by caregivers and their family.<sup>(7)</sup> Tunde-Ayinmode MF in Nigeria reported that (94%) of mothers of patients with SCD have a significant effect on the financial income compared with the control group<sup>(25)</sup>, and Amr et al in Saudi Arabia found that (68.3%) of families have impaired income due to SCD,<sup>(26)</sup> while Wonkam et al reported that (38.3%) of caregivers didn't lost income.<sup>(20)</sup> Wasomwe et al in Zambia reported that most of the families (76%) had low monthly income and the cost of caring for the child caused a huge financial burden to the families. Also increased number of affected siblings in the family had a significant impact on the financial scores because caring for these children needs more income and extra work to cover the finances of the disease.<sup>(19)</sup> Therefore, knowledge of the cost of care may assist providers in counseling patients and their caregivers about the likely consequences of the disease, both clinical and economic.<sup>(27)</sup>

Concerning routine family activities, the caregivers neglect other family members frequently and it was difficult for the patients to assist in household routines, these results are similar to that found by Wasomwe et al who reported that (76%) of families experienced strained interpersonal relationship within the home environment among the parents, siblings and other immediate family members due to living with a child affected with SCD.<sup>(19)</sup>

The parent's relation with their sick children and the feeling of neglect generated in other siblings is a major factor in family dysfunction, especially when occurred frequently and had been described as a risk factor in the psychosocial problems in SCD.<sup>(25)</sup>

The acute sickle cell painful crisis is the main cause of hospitalization, and is associated with high frequency of complications like ACS and around 33.4% of readmission within 30 days.<sup>(28)</sup> Its impact in SCD is significant regarding

financial strain and quality of life. <sup>(29)</sup> SCD cause frequent absence from the school (83.8%) mainly due to acute painful episodes. In addition, frequent VOC ( $\geq 3$ /year) have a significant impact on routine family activities including difficult to attend school. This result is similar to that reported by Jaiyesimi et al in Oman (83%). <sup>(30)</sup> Amr et al also found that adolescents with SCD showed a significant educational delay due to excessive absenteeism schools due to frequent hospitalization, emergency admissions, and checkup. <sup>(26)</sup> Thus, effective and rapid pain management will have a positive impact on psychosocial burden of the disease.

Half of families of children with SCD didn't experience tension at home, one third didn't show disagreement concerning their child illness and 20.7% only didn't report marital disharmony, although 70.7% have insignificant impact on family interaction burden. Adegoke et al reported a higher percentage of families who didn't report tension at home because of their child illness (70.2%), disagreement because of their child illness (73.3%) and marital disharmony (81.8%). <sup>(13)</sup>

Most of families in the current study experience insignificant impact on coping ability with SCD. This finding is similar to that reported by Tunde-Ayinmode MF in Nigeria <sup>(25)</sup>, while in Wonkam et al reported that (88.3%) of parents experience moderate to severe coping difficulties, and frequent VOC ( $\geq 3$  /year) was the main cause of these difficulties. <sup>(20)</sup>

The reason for this may be because of the Iraqi family structure, community, and religion. In Iraq, beliefs and thoughts are influenced mainly by religion, in which the parent's attitudes are positive as they show more of love and care for these children and they also accept their fate of having such children, which in turn influence the family interaction and coping strategies toward the illness.

Burden of patient condition during interview on different psychosocial variables was significant in financial and family at time of interview (steady versus crises state) on financial and family routines. <sup>(18)</sup> The cost of caring for the child with chronic illness such as SCD causes large financial strains to the families which could not be afforded by nonworking and/non-parent caregivers (grandmother). routine scores, Ohaeri et al in Nigeria also reported a significant impact of patient's condition

## CONCLUSIONS

SCD may be a source of psychosocial distress to the child's caregivers' especially in financial and routine family activities, therefore regular and sustained support system for the family helps relieve the burden of care.

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## APPENDICES

**Table 1: Selected Socio-Demographic and Clinical Variables of Patients with SCD and their Caregivers**

Variable	N. (%)	
Age (Year)	6-10	54(41.5)
	11-14	47(36.2)
	15-18	29(22.3)
Age at diagnosis (Year)	<1	28(21.5)
	1-2	73(56.2)
	>2	29(22.3)
Sex	Male	81(62.3)
	Female	49(37.7)
Educational level of caregiver	Illiterate	18(13.8)
	Primary school	71(54.6)
	Secondary school	37(28.5)
	Higher education	4(3.1)
Caregiver employment	Not working	44(33.8)
	Governmental	35(26.9)
	Self-employer	30(23.2)
	Retired	21(16.1)
Caregivers	Father	43(33)
	Mother	63(48.5)
	Others	24(18.5)
Number of siblings	None	19(14.6)
	1	33(25.4)
	≥ 2	78(60)
Number of other affected siblings	None	11(9.9)
	1	64(57.7)
	≥ 2	36(32.4)
Frequency of BT / year	None	23(17.7)
	<3	63(48.5)
	≥ 3	44(33.8)
Frequency of hospitalization / year	None	21(16.2)
	<3	61(46.9)
	≥ 3	48(36.9)
Frequency of VOC / year	None	16(12.3)
	<3	83(63.8)
	≥ 3	31(23.9)

**Table 2: Impact of SCD on Psychosocial Indices of Families**

Variable	Never Occurred N. (%)	Occurred Occasionally N. (%)	Occurred Frequently or Regularly n. (%)
<b>Family Finance</b>			
Lose income	14(10.8)	28(21.5)	88(67.7)
Took out a loan	18(13.8)	31(23.8)	81(62.4)
Expenses of child's illness affect family needs	23(17.7)	18(13.8)	89(68.5)
<b>Routine Family Activities</b>			
Neglect of other family members	5(3.8)	38(29.3)	87(66.9)
Difficulty for child to assist in household routines	15(11.5)	33(25.4)	82(63.1)
Difficulty to attend school because of child illness	4(3)	17(13.2)	109(83.8)
Child's illness disturbs activities at home	61(46.9)	43(33.1)	26(20)

Table 2: Contd.,			
Difficulty engaging in other gainful activities	61(46.9)	53(40.8)	16(12.3)
Family Interactions			
Child illness cause tension at home	65(50)	29(22.3)	36(27.7)
Child illness cause disagreement	43(33)	57(43.8)	30(23.2)
Child illness cause marital disharmony	27(20.7)	67(51.6)	36(27.7)
Family Coping Abilities			
Difficulty coping with the child illness	15(11.5)	81(62.3)	34(26.2)
Difficulty accepting responsibility for care of illness	71(54.6)	23(17.7)	36(27.7)
Feeling depressed about the illness	67(51.5)	31(23.8)	32(24.7)
Feeling angry with self or the child because of the illness	73(56.2)	27(20.8)	30(23)
Feeling stigmatized because of the illness	66(50.8)	26(20)	38(29.2)

Table 3: Psychosocial Burden Score of the Four Domains

Score	N. (%)	Mean
Financial Burden		
0-3	6(4.6)	6.11± 1.57
4-6	71(54.6)	
7-9	53(40.8)	
Family Interaction Burden		
0-3	92(70.7)	5.70±1.61
4-6	25(19.3)	
7-9	13(10)	
Routine Family Activity		
0-5	31(23.8)	10.03 ± 2.17
6-10	54(41.5)	
11-15	45(34.7)	
Family Coping Ability		
0-5	96(73.8)	4.93 ± 1.51
6-10	27(20.8)	
11-15	7(5.4)	

Table 4: Impact of Patient's Condition during Interview on Psychosocial Variables

Variables	Steady State (N. 107)	In Crises (N. 23)	P Value
Financial burden score	6.22±2.55	8.60±1.74	0.023
Routine family activity burden score	9.81±1.33	11.22±1.23	0.042
Family interactions burden score	4.8±1.26	5.72±1.61	0.067
Family coping burden score	4.92±1.56	5.00±1.86	0.641

T-test was used

**Table 5: Different Socio-Demographic Variables on Effect of Psychosocial Burden Score**

Variable		Financial Burden	P Value	Family Interaction Burden	P Value	Routine Family Activities Burden	P Value	Family Coping Ability Burden	P Value
<b>Educational level of caregiver</b>	Illiterate	6.3±1.8	0.08	5.11±1.64	0.08	8.8±2.3	0.07	5.16±1.58	0.295
	Primary school	5.6±1.6		5.64±1.55		8.5±2.6		5.08±1.72	
	Secondary school	5.4±1.5		6.29±1.64		8.2±2.5		4.51±0.98	
	Higher education	5.2±1.7		5.25±0.50		8.6±2.3		5.25±3.30	
<b>Caregiver employment</b>	Not working	6.8±1.7	0.07	5.56±1.75	0.07	10.3±1.9	0.07	4.95±1.46	0.771
	Governmental	6.5±1.4		6.11±1.69		10.2±1.7		4.71±1.70	
	Self-employer	6.2±1.2		6.10±1.15		10.2±2.29		5.03±1.54	
	Retired	5.4±1.8		5±1.44		8.7±2.23		5.14±1.82	
<b>Type of caregiver</b>	Father	4.4±1.5	0.03	5.73±1.56	0.93	10.8±2.2	0.06	5.03±1.68	0.757
	Mother	4.7±1.8		5.76±1.68		10.5±2.6		4.90±1.50	
	Others	6.6±1.6		5.75±1.62		10.7±2.5		5.75±1.56	
<b>Number of affected siblings</b>	None	5.3±1.2	0.06	6.27±1.79	0.45	9.2±1.6	0.02	5.45±1.75	0.450
	1	6.3±1.1		5.79±1.64		9.3±1.5		4.96±1.56	
	≥2	6.8±1.8		5.58±1.52		11.7±1.8		4.80±1.61	
<b>Frequency of hospitalization /year</b>	None	6.5±1.5	0.04	5.80±1.69	0.97	9.2±1.3	0.03	4.33±1.24	0.084
	<3	6.3±1.2		5.77±1.50		9.4±2.1		5.21±1.88	
	≥3	6.7±1.5		5.68±1.71		11±1.4		4.85±1.25	
<b>Frequency of BT/year</b>	None	4.2±1.5	0.06	5.17±1.77	0.16	10.8±2.2	0.07	4.78±1.24	0.684
	<3	4.5±1.8		5.84±1.37		10.5±2.6		5.06±1.89	
	≥3	6.3±1.7		5.90±1.78		11±2.5		4.84±1.27	
<b>Frequency of VOC/year</b>	None	6.5±1.3	0.06	5.21±1.50	0.42	9.1±1.5	0.04	5±1.86	0.405
	<3	6.3±1.2		5.65±1.70		9.4±1.5		4.80±1.35	
	≥3	6.7±1.5		6.06±1.45		11.9±1.7		5.28±1.86	

ANOVA test was used-

